

## ORIGINAL ARTICLE

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## Breast cancer survivors and behavior: cancer care in the time of COVID-19 in Indonesia

Widyanti Soewoto<sup>1\*</sup> 

### ABSTRACT

The COVID-19 pandemic caused significant disruptions in cancer care, and preliminary research suggests that these disruptions are associated with increased levels of psychosocial distress among cancer survivors. Indonesia initially reported positive cases in early March 2020, followed by regular extensive occurrences across 34 provinces. The disease causes acute respiratory failure among people with specific comorbidities, including geriatric disorders, diabetes, cardiovascular and respiratory diseases, and cancer. Consequently, the patients' conditions become more severe, possibly leading to a higher mortality rate. Individuals with cancer are at particularly elevated risk of a severe course of COVID-19 because they tend to be of older age and are at a greater risk for needing intensive care and for mortality. A reasonably good comprehension of the current COVID-19 outbreak, poor awareness of the primary disease and subsequent therapy program, and minimal understanding of the importance of continuing treatment during the pandemic are the probable factors causing the fear of contracting the COVID-19 virus that poses a significant threat of aggravating the existing breast cancer conditions in most patients. This anxiety shows a drastic impact in altering the behavioral patterns of survivors undergoing therapy. There is a very good understanding of how it is caused by the SARS-COV2 virus. Meanwhile, there is a severe lack of understanding of cancer and the therapeutic program. The patients are more afraid of contracting this virus than they are of their cancer. Patients prefer development of their cancer to contracting the SARS-COV2 virus. Therefore, massive education and supervision are needed for cancer patients to understand the COVID-19 pandemic and ensure that routine checks are appropriately managed.

**Keywords:** COVID-19, breast cancer, fear, cancer therapy

<sup>1</sup>Sub Division of Oncology Surgery, Faculty of Medicine, Sebelas Maret University, Indonesia

**\*Correspondence:**

Widyanti Soewoto  
Jl Slamet Riyadi no 419 Makamhaji  
Kartasura Surakarta Jawa Tengah  
Indonesia  
Phone: +62817272338,  
Email: widyanti\_s@staff.uns.ac.id  
ORCID ID: 0000-0003-2513-5801

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## INTRODUCTION

Millions of casualties have been reported globally since the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) was first discovered in December 2019 in Wuhan, China. This virus is responsible for the rapid spread of the COVID-19 pandemic through airborne contact with infected persons or contaminated surfaces. Also, the disease causes acute respiratory failure among people with specific comorbidities, including geriatric disorders, smoking habits, hypertension, diabetes, cardiovascular and respiratory diseases, and cancer.<sup>(1)</sup> As a consequence, the patients' conditions become more severe, possibly leading to a higher mortality rate. Furthermore, every sector of human endeavor has drastically changed, with multiple deaths attributed to the fear of contracting the virus, particularly in persons diagnosed with various comorbidities.<sup>(2-4)</sup> The World Health Organization (WHO) has declared the COVID-19 disease a public health emergency of international concern (PHEIC). Indonesia initially reported positive cases in early March 2020, followed by regular extensive occurrences across the 34 provinces. Daily, 223 new patients were observed in less than a year, with an accumulated total of 3,886, the highest rate being in East Java. This infection alters diverse societal aspects, specifically in the health sector.<sup>(4,5)</sup>

Various methods have been applied to reduce the coronavirus spread and mortality rate. However, the disease appears very complex because the pathophysiology and exact cause are relatively novel. The detection, treatment, prevention, and other related activities are undergoing thorough research. This is because the possibility of several mutations of SARS-CoV-2 poses a severe threat to the effective management of the growing outbreak.<sup>(4-6)</sup>

Community awareness and attitude are significant factors influencing the compliance on preventive measures against the spread of the virus. The fear of contracting the virus is attributed

to the increasing rate of daily positive cases and is mainly observed among persons with comorbid diseases such as cancer.<sup>(7,8)</sup> This pandemic has greatly affected cancer patients who regularly come to health services to undergo cancer therapy, many of whom have postponed their therapy due to fear of infection. Only cancer patients with severe conditions are now coming to the health service. Likewise with new cases, patients delay treatment as much as possible and only when the complaints become more severe, do they dare to come to the health service.

Several strategies to prevent further COVID-19 transmission and mortality rates have been initiated at the national and local levels by the Indonesian government. One of the significant policies involved strict data collections based on specific locations with high numbers of infectious or suspicious cases, time of occurrence, confirmed persons' status or condition, and direct or indirect contacts. Furthermore, isolation centers were established when a total of 5 or more cases had been reported.<sup>(9)</sup> In a previous study, we distributed the Universitas Sebelas Maret - Cancer Attitude Satisfaction Knowledge Questionnaire (UNS - CASKQ14) as a google form via the Whatsapp application to breast cancer patients throughout Indonesia. The UNS - CASKQ14 is an easy-to-understand Indonesian-language questionnaire, containing an assessment of the quality of and compliance with treatment of cancer survivors in undergoing therapy programs during the COVID-19 pandemic. This study was to determine the behavior patterns of breast cancer survivors in Indonesia, whether there is anxiety about contracting COVID-19 or whether the anxiety about cancer eliminates the fear of contracting COVID-19.<sup>(10)</sup>

Oncology specialists as well as other providers regularly involved in the diagnosis, active treatment, and longitudinal follow-up of patients with breast cancer must consider how to 1) balance a delay in breast cancer diagnosis or treatment against the risk for a potential COVID-19 exposure, 2) mitigate the risks for significant care disruptions associated with social distancing

behaviors, and 3) manage the appropriate allocation of limited health care resources in this unprecedented time of health care crisis.

Hopefully, we can see how the behavior patterns of cancer survivors in undergoing their therapy, so as to reduce delays in the enforcement of diagnosis and therapy in cancer patients, prevent cancer patients from being infected with the Covid-19 virus and medical personnel in health services who work a little more effectively during the pandemic.

### **Management of breast cancer during the COVID-19 pandemic**

The COVID-19 pandemic appears not to subside and has recorded approximately 4 million global cases in virtually two years of existence. Indonesia tends to experience rapid and increasing mortality rates daily due to human-to-human transmission. In mid-March 2020, the government imposed lockdown measures in the form of cessation of most activities, strict quarantine, and self-isolation.<sup>(11-14)</sup>

All hospitals, from referral to minor hospitals, and other health facilities and medical personnel resources, are of utmost importance during this pandemic. As a significant change in facing this pandemic, most health facilities have been turned into special Covid-19 medical centers. Some medical services began to be limited from observing the gravity of the disease. Patients with life-threatening conditions were to be prioritized, while non-emergency cases were to be postponed.<sup>(15-18)</sup>

Breast cancer is most predominant in women worldwide and has the highest incidence among all cancers diagnosed in Indonesian women. Over 65,000 new cases were reported in 2020, with the result that breast cancer has become the second malignant cause of death after lung cancer. The COVID-19 pandemic is also known to significantly affect breast cancer patients and survivors, particularly in regard to managing schedule and therapy. Individuals that have not been diagnosed also experience the impact and are afraid of visiting health facilities.<sup>(19,20)</sup> From

the medical aspect, during this pandemic, medical personnel and health facilities had to make some modifications in treating and handling patients to minimize the risk of exposure and prevent medical personnel from being infected. Therefore during this pandemic, there is a challenge in conducting and managing patients.<sup>(21,22)</sup> Several new guidelines for cancer patients and survivors were made during this pandemic, with the aim that cancer patients and survivors who have severe comorbidities for COVID-19 do not come to health facilities, because these health facilities are a source of Covid-19 transmission during the pandemic. In addition, this is also to reduce excessive contact of medical personnel with patients whose infection status is unknown.<sup>(23,24)</sup>

The principles of breast cancer management during the COVID-19 pandemic may continue to be instituted as usual according to the applicable guidelines and taking into account the conditions of the hospital and the local area. If the patient's condition allows, endocrine therapy is safer to administer in the pandemic situation, if it is necessary to postpone treatment that results in the patient being hospitalized.<sup>(23,24)</sup>

According to their treatment, breast cancer patients are broadly grouped into patients not on therapy and patients on therapy. Patients with "active disease" should still undergo surgical treatment, chemotherapy and radiotherapy, biologic therapy, endocrine therapy, and immunotherapy (either as an adjuvant or neoadjuvant). This should be done with the application of strict health procedures, namely avoiding crowded places; wearing personal protective equipment when visiting a hospital for visits and treatment; washing hands properly according to WHO indications; not contacting friends and relatives with COVID-19 symptoms or residing in a COVID-19 endemic zone.<sup>(25-27)</sup>

Patients at high risk for contracting the COVID-19 virus are those who are currently receiving or have received chemotherapy in the past three months, patients who have received extensive radiotherapy, patients who have had a bone marrow or stem cell transplant in the last

six months, or who are still taking immunosuppressive drugs, patients with some types of blood or lymphatic cancer that impair the immune system, even if they do not require treatment (for example, chronic leukemia, lymphoma or myeloma).<sup>(23,26)</sup> During the pandemic, cancer patients are grouped into three groups: high priority, medium priority, and low priority. This grouping is based on the patients' condition, both outpatients, patients needing diagnostic and supporting examinations, and patients with planned surgery, radiotherapy, and chemotherapy.<sup>(28)</sup>

High-priority patients are those with life-threatening, clinically unstable, or intolerable conditions. Even if medical personnel are minimal, treatment must be carried out immediately to control the developing disease, relieve symptoms, or preserve the patient's life. Even a short delay will significantly change the prognosis for the worse.<sup>(29)</sup>

A medium priority condition is one that is not immediately life-threatening, but treatment or services should not be postponed indefinitely until the end of the pandemic. Most breast cancer patients will be included in the medium priority category. If conditions are unfavorable, treatment for medium priority patients may be delayed for some time during the pandemic. A short delay (6-12 weeks) will not affect the patient's prognosis. A longer delay may affect outcomes in some medium-priority patients. Patients with medium priority status can become top priority if their condition aggravates.<sup>(28,29)</sup> Low priority patients are those in whom treatment or service can be suspended indefinitely until the pandemic ends without adversely affecting cancer prognosis.

Some cancer therapies have been revised by adjusting patients' environmental conditions and COVID-19 infection status. Several types of surgery have been delayed, i.v. line chemotherapy was modified to oral, and radiotherapy in some instances was also postponed. In addition, the follow-up schedule for cancer monitoring was altered, while several

guidelines recommended telemedicine instead of face-to-face consultations.<sup>(24)</sup>

The UNS-CASKQ14 refers to a questionnaire used in a study assessing the quality of and compliance to treatment of cancer survivors who are considering therapy during the present pandemic. This survey was conducted to determine the coronavirus impact on cancer survivors based on knowledge, attitude, practice, and compliance to clinical therapy. The analysis was expected to determine the behavioral patterns of breast cancer survivors in Indonesia, precisely in remote areas with high levels of anxiety of contracting COVID-19 or cancer.<sup>(30-34)</sup>

### **Breast cancer during the COVID-19 pandemic in Indonesia**

Indonesia is an archipelagic country comprising 17,504 large and small islands, with 45% and 55% having named and unnamed status, respectively.<sup>(35)</sup> However, several limitations have been observed, including the uneven distribution of facilities and infrastructure in terms of transportation, economy, education, information, and social services, with certain regions classified as remote. According to Presidential Regulation Number 63 of 2020 on the Designation of Underdeveloped Regions for 2020-2021, 62 locations in several provinces were designated as underdeveloped (Figure 1).<sup>(35)</sup>

Based on Law Number 36 of 2009 on Health, health service facilities consist of first-level health facilities, including public health centers, primary clinics, private medical/dental practices, and advanced referral health facilities, such as general and special hospitals. Also, by December 2019, the total number of public health centers was precisely 10,134, comprising 6,086 inpatients and 4,048 outpatients (Figure 2).<sup>(36)</sup>

The fulfillment of immediate health care demands is generally presented from the ratio of public health centers to subdistricts of 1:4 in 2019. This indicates an ideal proportion of at least one public health center in 1 subdistrict and has been accomplished nationally, but with uneven distribution. Furthermore, community accessibility



Figure 1. Map of Indonesia with 34 provinces.<sup>(35)</sup>

is influenced by various factors, including geographical conditions, area size, basic facilities, infrastructure availability, and socio-economic and regional progress. The lowest ratio occurs in West Papua province, where community access to primary health care facilities is currently not ideal. A ratio below 1 showed that not all sub-districts have public health centers. At the same time, the complex geographical conditions and the low average socio-economic development in the area demonstrate the need to improve access to medical services. <sup>(31,36,37)</sup>

Hospitals are grouped into Class A, B, C, and D, based on facilities and service capabilities. Sequentially, the maximum number is class C hospitals at 51.6%, followed by class D, B, and A hospitals at 29.4, 14.9, and 2.1%, respectively. According to the WHO, the standard for community needs for referral and individual health services in an area is obtained from the ratio of

hospital beds to inhabitants of 1:1,000. This ratio was above 1 per 1,000 population between 2014 and 2019, representing the minimum WHO benchmark. However, the standard has not been fulfilled in 8 provinces, including West Nusa Tenggara (0.74), East Nusa Tenggara (0.83), Banten (0.87), West Java (0.87), Lampung (0.90), West Sulawesi (0.92), Central Kalimantan (0.94), and Riau (0.98). <sup>(36,37)</sup>

The proportion of medical personnel in all provinces appears to be uneven. Approximately 57.2% of these workers are located on the island of Java, with the highest number in the provinces of Jakarta, East Java, and Central Java. Similarly, Jakarta and East Java record the maximum number of specialist doctors. Because the provinces of Papua, Maluku, Sulawesi, and Kalimantan have a minor proportion of the population, it is not surprising that the minimum number of specialist doctors is found in West

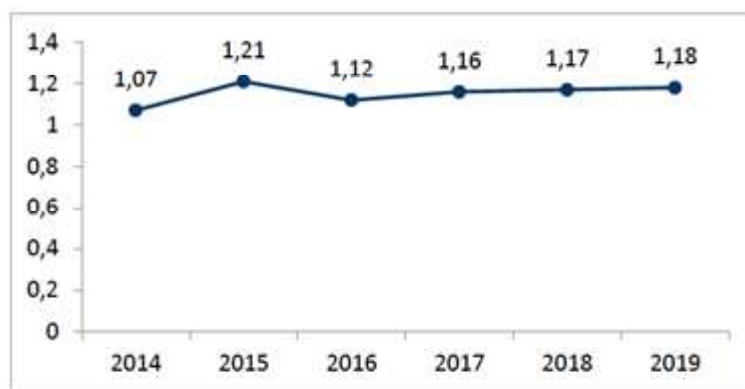


Figure 2. The hospital beds per 1,000 population in Indonesia from 2014 – 2019.<sup>(36)</sup>

Sulawesi and Maluku, although the majority of the doctors are employed in class A and B hospitals. <sup>(36,37)</sup>

Indonesia exhibits the optimal frequency of breast cancer in women, with the second-highest mortality rate after lung cancer. Health workers and facilities must initiate immediate actions and ensure that these patients and survivors have a high probability of obtaining proper care and therapy. During treatment, adequate protective measures are also necessary to guarantee that the health workers are not infected with COVID-19 or other viruses. <sup>(38)</sup> There are challenges in patients as well as medical personnel, so that the professionalism of medical personnel and the priority of breast cancer patients need to adjust to local conditions during this pandemic, in order to minimize the risk of cancer development that must be balanced by reducing the risk of contracting the SARS-CoV-2 virus, both for the patients and the involved medical personnel. For the priority of breast cancer treatment, the patients are categorized into high risk, moderate risk and low risk patients. <sup>(32)</sup>

High risk patients with are patients with life-threatening, clinically unstable, or completely intolerable conditions. Even a short delay will significantly change the prognosis. This group, requiring immediate treatment to control a developing disease, symptomatic help, or life support, is given top priority, even if resources become scarce. Moderate risk patients are patients with conditions that are not directly life-threatening but treatment or services should not be postponed indefinitely until the end of the pandemic. Most patients with breast cancer fall into this group. Low-risk patients are breast cancer patients in whom certain treatments or services can be suspended indefinitely until the pandemic ends without any adverse impact on their cancer. With the rearrangement in all lines of health services, especially the handling of breast cancer patients, it is hoped that the Covid-19 pandemic will not cause the number of breast events to increase, nor will there be an increase in the mortality rate.

## **Factors affecting attitudes of breast cancer patients and survivors during the COVID-19 pandemic**

### **1. Understanding of the pandemic**

The WHO declaration of COVID-19 as a global pandemic has compelled the Indonesian government to state the condition as a non-natural national disaster. In collaboration with local authorities, the National Natural Disaster Management Agency (BNPB) conducts socialization on COVID-19 and its development and offers necessary measures to prevent further transmission. During the pandemic, various governmental actions were implemented, with the primary objective of prioritizing policies in health management over other sectors. <sup>(39)</sup>

The central government also initiated health awareness campaigns across remote regions, using electronic media, television, radio, and social networks to complement local governments and health workers' similar but direct socialization efforts. COVID-19 also requires new insights into pathophysiology and management, and therefore, diverse information is generated as experts continue to research the best measures of combating the virus. However, every avenue is currently under research, and no concrete scientific evidence has been obtained, leading to a very vulnerable state of possible misinformation. <sup>(5,6)</sup> The limitations of facilities and infrastructure in specific remote communities have created complications in comprehending COVID-19. This circumstance reduces public awareness in controlling transmission and early detection, leading to excessive panic due to misinformation. The condition also triggers stress and anxiety with a significant impact on the declining immune system of cancer patients and survivors. <sup>(40,41)</sup> Medical care observably changed during the COVID-19 pandemic, with adverse effects on susceptible patients, specifically older cancer patients. These alterations in the primary treatment of breast cancer and exposure to SARS-CoV-2 infection resulted in an extensive stressful situation. A recent survey of increasing COVID-19 stress among patients awaiting

surgery detected fears that the pandemic will likely cause delays in their oncological care, leading to higher disease susceptibility, particularly in women with invasive cancer.<sup>(25,42)</sup>

During the outbreak, hospital resources were reorganized into elective and semi-elective procedures to meet the needs of patients in critical conditions. Furthermore, scarcity of supplies can delay diagnostic evaluation and breast cancer treatments. In addition, COVID-19 anxiety plays a role in the therapeutic timing, as the early pandemic witnessed several patients requesting immediate surgery due to the high risk of suspending treatments. Conversely, certain breast cancer patients refused or delayed therapy, including surgery.<sup>(43,44)</sup>

## **2. Understanding of the required therapy program**

The relevant information or therapy for breast cancer requires proper delivery, depending on the patients' education, occupation, and customs. Poor communication or the differences in local languages are possible factors causing information deficiency. However, family members believe that patients do not need to be aware of the diseases or therapeutic processes, to reduce unnecessary worries. Doctors are prohibited from disclosing sensitive information to external parties, even to certain family members. Inadequate or absent understanding among the patients about the treatment possibly leads to failure, therefore the cancer tends to become more progressive, with a high mortality risk.<sup>(45-50)</sup> The greatest challenge for cancer patients during the pandemic is acquiring the necessary medical services, as a visit to hospitals extends the risk of contracting COVID-19. Consequently, certain patients are advised not to visit hospitals or leave their homes. At the same time, a number of therapy schedules have been delayed due to several regions implementing the quarantine measures.<sup>(51-53)</sup>

A significant alternative recommended by health services involves the use of telehealth, or telemedicine, where people living with cancer can consult medical personnel, as this process

significantly reduces oncology patients' exposure to COVID-19.<sup>(54)</sup> Similar to other technology, accessibility appears to be the primary concern of telemedicine. Despite the ease of establishing contacts, the connection in remote areas is typically unstable. Another challenge is based on the economic conditions of different patients, as individuals with minimal socioeconomic backgrounds have constrained internet access. Meanwhile, the category with sufficient socioeconomic and internet facilities prefers to receive treatment remotely, which mainly involves reporting the last complaint, followed by subsequent drug delivery.<sup>(55-60)</sup>

Telemedicine is not applied in certain areas because the majority of sick persons prefer direct treatment schedules with the doctor. All the complaints felt at home tend to disappear suddenly when interacting physically with medical personnel. Therefore, it is strongly observed that cancer patients prefer visiting health facilities.<sup>(61)</sup>

## **3. Understanding the importance of continuity of treatment during the pandemic**

The unprecedented burden of COVID-19 on healthcare systems worldwide generated significant implications, particularly in caring for cancer patients. First, limited data show that cancer patients are more susceptible to an aggravated state of the coronavirus infection, including a greater need for breathing apparatus such as ventilators and a high mortality rate. Second, early cancer diagnosis appears to be delayed as screening programs and diagnostic services have been reduced or suspended in various countries. Patients who are aware of the high infection risk are more reluctant to visit health facilities. Third, the current guidelines for cancer treatment are changing to minimize the potential exposure and infection risk during surgery or radiation therapy. Fourth, certain aspects of current clinical care have been prioritized to enable the health system to respond to the COVID-19 pandemic, resulting in sub-optimal or delayed medical attention. Fifth, cancer research is postponed, leading to a reduction in the current

therapeutic options that could have been used and jeopardizing the development of long-term therapies.<sup>(22,62)</sup>

Governments, health facilities, and professional organizations have developed guidelines for managing the continuous welfare of cancer patients in the current pandemic. Routine visits are conducted by telephone or rescheduled, and oral medications are delivered to individual homes to prevent further spread. In addition, surgeries, tissue sampling, or other investigations are performed at the local health facility. Meanwhile, cancer multidisciplinary team meetings are conducted via virtual platforms, as individual treatment plans are also modified.<sup>(63-64)</sup> Due to misleading information about the virus, the confusions and inactions at the advent of the pandemic generated a higher possibility of poorer outcomes for vulnerable populations, including cancer patients. Furthermore, the world also faces an 'infodemic' condition, where accessibility to selective and quality information and understanding appears critical in considering decisions and actions under similar crises. This situation illustrates the need to increase health literacy to enable national health authorities. Another obstacle is conducting a precise clinical examination remotely, as this process often reveals early signs that potentially lead to new investigations. The greatest challenge is probably the selection of patients that are asked to report to the clinic and the category that stays at home. Furthermore, the patients are divided into three subgroups with different recommendations, including patients in the follow-up phase or patients on oral therapy with newly diagnosed cancer under curative care and metastatic cases receiving palliative care.<sup>(64)</sup>

A basic priority is maintaining high-quality cancer care for all patients. Local factors involving infrastructure, resources, personnel, and social and geographic constraints create differences in access and quality of care, particularly for vulnerable patients, including the patients from rural areas that are culturally, socially, and linguistically diverse. In addition, digital tools

provide solution strategies to address logistical challenges contributing to the apparent gaps.

Overall the pandemic changed the behavior of cancer patients undergoing therapy, due to the lack of information about COVID and its effects on cancer, the ignorance of patients as to how they should behave, whether cancer therapy should stop or continue, the lack of education on how patients should continue to undergo therapy for their cancer but also avoid transmission of the SARS-COV2 virus. In addition, patients also feel that there is no organization that accommodates them so that they cannot ask questions. There is also the factor of limited internet connection that makes it difficult for patients to share news about their illness.

## CONCLUSION

It can be concluded that there is a very good understanding of how the SARS-COV2 virus is transmitted. Meanwhile, the understanding of cancer and the therapeutic program is very lacking. The patients are more afraid of contracting this virus than they are of their cancer. Patients prefer the development of their cancer to contracting the SARS-COV2 virus. It is very necessary to increase the provision of education by medical personnel so that patients really understand about the disease and the stages of therapy they will undergo. It is very necessary to evaluate periodically the patients' understanding of their cancer.

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The authors declare no competing interests.

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